



**NJ Department of Health
Governor's Council for Medical Research and Treatment of Autism
Council Meeting Minutes (ratified)
May 26, 2016**

Council Members Present

Michael Aquino, MD, F.A.C.G., Senate President Appointee; Partner, Shore Gastroenterology Associates, Cofounder, VP of Operations, Pathology Solutions

***Caroline Eggerding, MD**, Healthcare Organization Representative; Division Head, Department of Pediatric Neurology and Development, Cooper Children's Regional Hospital

Susan P. Evans, Ed.D., Commissioner of Health Appointee; Education Program Specialist for Early Intervention Program, NJ Department of Health

Wilma Judith Friedman, Ph.D., Academic Institution Representative; Professor, Department of Biological Sciences, Rutgers University

B. Madeleine Goldfarb, MA, Autism Organization Representative; Founder/Director of the Noah's Ark Institute

Ketan Kansagra, MD, FAAP, Academic Institution Representative; Division of Neonatal Medicine, Children's Hospital of New Jersey at Newark Beth Israel Medical Center

Thomas V. Macchiaverna, MA, Public Member Representative; Special Education Teacher

Dana E. Spett, MSW, Autism Organization Representative; Founder/Executive Director, Pony Power Therapies (present via teleconference)

Samuel Sheng-Hung Wang, Ph.D., Academic Institution Representative; Professor, Department of Molecular Biology and Princeton Neuroscience Institute, Princeton University

*Denotes Council Chairperson

Absent

Elizabeth K. Bell, BS, Public Member - Individual or Family Member with Autism Representative; Volunteer and Independent Contractor with Autism Speaks

Cheryl F. Dreyfus, Ph.D., Academic Institution Representative; Professor and Chair,
Department of Neuroscience and Cell Biology, Rutgers University, Robert Wood Johnson
Medical School

Gary Weitzen, BA, Autism Organization Representative; Executive Director of POAC (Parents
of Autistic Children)

NJ Department of Health (DOH) Attendees

Martin T. Zanna MD, MPH, Acting Executive Director
Governor's Council for Medical Research and Treatment of Autism

Linda N. Bocclair, M.Ed., MBA, Executive Assistant
Governor's Council for Medical Research and Treatment of Autism

Mary Ray, Contract Administrator 2
Governor's Council for Medical Research and Treatment of Autism
Commission on Brain Injury Research and Commission on Spinal Cord Research

Daphne Robinson, Ph.D., Consultant
Scientific Planning Consulting

Public Attendees

Gerard Costa, Ph.D., Center for Autism and Early Childhood Mental Health at Montclair State
University and Principal Investigator, NJ ACE Coordinating Center

Karen Hood-Kasim MPH, Project Coordinator, NJ ACE Coordinating Center

Eileen McKeating, Ph.D., Research Associate, NJ ACE Coordinating Center

Anna Dulencin, Ph.D., Biomedical Research Consultant, NJ ACE Coordinating Center

Charles Matteis, Ph.D., Strategic Planning Consultant, NJ ACE Coordinating Center

I. Welcome - Council Chairperson, Dr. Caroline Eggerding called the meeting to order at 6:05
PM and welcomed everyone.

II. Public Meetings Act Announcement- Dr. Eggerding read the Public Meetings Act, followed
by roll call.

III. Approval of the March 28, 2016 Council Meeting Minutes-Dr. Eggerding called for a
motion to approve the minutes. MOTION by Dr. Kansagra to approve the minutes was seconded
by Dr. Friedman.

MOTION to approve the minutes was passed with four in favor and four abstentions.

VI. Continuation funding for 2012, 2013 and 2015 grantees

The Council was requested to consider continuation funding for one 2012 grant, one 2013 grant and twelve 2015 grants.

Grant # CAUT15APL021

Dr. Eggerding called for a motion to approve Grant # CAUT15APL021, *Using SMART Treatment Design to Evaluate Applied Behavior Analysis Interventions on Communication in Preschool Children with Autism*, for year two continuation funding.

MOTION by Ms. Goldfarb to approve CAUT15APL021 for year two continuation funding was seconded by Dr. Evans.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for year two for Grant #CAUT15APL021 was approved with seven of the eight members in favor. The eighth member arrived later.

Grant # CAUT15APL012

Dr. Eggerding called for a motion to approve Grant # CAUT15APL012, *Development of Early Markers of Autism Spectrum Disorder (ASD)*, for year two continuation funding.

MOTION by Dr. Evans to approve CAUT15APL012 for year two continuation funding was seconded by Ms. Goldfarb.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for year two for Grant #CAUT15APL012 was approved with six members in favor and one recusal. The eighth member arrived later.

Grant # CAUT15APL038

Dr. Eggerding called for a motion to approve Grant # CAUT15APL038, *Bridging behavior and genetics through sensory-motor electrophysiology*, for year two continuation funding.

MOTION by Ms. Goldfarb to approve CAUT15APL038 for year two continuation funding was seconded by Dr. Kansagra.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for year two for Grant #CAUT15APL038 was approved with seven members in favor and one recusal. The eighth member arrived later.

Grant # CAUT15APL014

Dr. Eggerding called for a motion to approve Grant # CAUT15APL014, *Exploring the experiences of diverse families of children newly diagnosed with ASD in New Jersey* for year two continuation funding.

MOTION by Dr. Evans to approve CAUT15APL014, for year two continuation funding was seconded by Ms. Goldfarb.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for year two for Grant #CAUT15APL014 was approved with seven members in favor and one recusal.

Grant # CAUT15APL041

Dr. Eggerding called for a motion to approve Grant # CAUT15APL041, *Neurobiology of idiopathic autism: Cellular and molecular phenotypes of common copy number variant (CNV), 16p11.2* for year two continuation funding.

MOTION by Ms. Goldfarb to approve CAUT15APL041 for year two continuation funding was seconded by Dr. Kansagra.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for year two for Grant #CAUT15APL041 was approved with seven members in favor and one recusal.

Grant # CAUT15APL026

Dr. Eggerding called for a motion to approve Grant # CAUT15APL026, *Identifying Sequence Variants Related to the Core Behavioral Domains of Autism* for year two continuation funding.

MOTION by Dr. Evans to approve CAUT15APL026 for year two continuation funding was seconded by Ms. Goldfarb.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for year two for Grant #CAUT15APL026 was approved with seven members in favor and one recusal.

Grant # CAUT15APL022

Dr. Eggerding called for a motion to approve Grant # CAUT15APL022, *METABOLIC PERTURBATIONS WITH AUTISM INDUCED BY PLASTICIZERS* for year two continuation funding.

MOTION by Dr. Kansagra to approve CAUT15APL022 for year two continuation funding was seconded by Dr. Friedman.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for Grant #CAUT15APL022 was approved with all in favor.

Grant # CAUT15APL013

Dr. Eggerding called for a motion to approve Grant # CAUT15APL013, *Sulforaphane in autism. A treatment trial to confirm phenotypic improvement with sulforaphane treatment in a NJ population of individuals with autism* for year two continuation funding.

MOTION by Ms. Goldfarb to approve CAUT15APL013 for year two continuation funding was seconded by Dr. Kansagra.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for year two Grant #CAUT15APL013 was approved with seven members in favor and one recusal.

Grant # CAUT15APL046

Dr. Eggerding called for a motion to approve Grant # CAUT15APL046, *Piloting Electrophysiologic Biomarkers for ASD and Related disorders in Premature and LBW infants* for year two continuation funding.

MOTION by Ms. Goldfarb to approve CAUT15APL046 for year two continuation funding was seconded by Dr. Evans.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for year two for Grant #CAUT15APL046 was approved with seven members in favor and one recusal.

Grant # CAUT13APS025

Dr. Eggerding called for a motion to approve Grant # CAUT13APS025, *Development of a new autism screening tool for traditionally underserved families* for year four continuation funding.

MOTION by Dr. Friedman to approve CAUT13APS025 for year four continuation funding was seconded by Ms. Goldfarb.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for year four for Grant #CAUT13APS025 was approved with all members in favor.

Grant # CAUT12APS006

Dr. Eggerding called for a motion to approve Grant # CAUT12APS006, *Elucidating Genetic Components of Autism and Related Disorders* for year five continuation funding.

MOTION by Dr. Kansagra to approve CAUT12APS006 for year five continuation funding was seconded by Ms. Goldfarb.

Dr. Costa recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for year five Grant #CAUT12APS006 was approved with seven members in favor and one recusal.

Autism Health Needs Medical Homes Grants

Dr. Zanna presented an overview of the Autism Health Needs Medical Homes grants noting the grants differ from Council's other grants in that the Autism Health Needs Medical Homes RFA defines specific deliverables required to establish a system for the management of patients with ASD. The grantee writes a charter with several components including a governance structure that defines the mechanisms, processes and relations by which the project is controlled and directed. Examples of other deliverables include "as is" and "to be" workflow maps, assessment of the HIT system and an action plan using the "to be" workflow map to provide details of the interventions. In addition, each grantee defined objectives specific to their organizations.

Grant # CAUT15APL020

Dr. Eggerding called for a motion to approve the grant *Children's Specialized Hospital Pediatric Primary Care ASD Medical Home* for year two continuation funding.

MOTION by Ms. Goldfarb to approve the grant *Children's Specialized Hospital Pediatric Primary Care ASD Medical Home* for year two continuation funding was seconded by Dr. Friedman.

Dr. Zanna commented that the grantee exceeded expectations in addressing the deliverables with details that clearly illustrates their understanding of the grant requirements. He acknowledged the work of the project manager and the co-investigator in addressing the deliverables. Dr. Zanna also referred Council to the grantee's Executive Summary for the successes and challenges with their project specific objective to improve the quality of and access to care for children by creating and implementing an enhanced care coordination program. He recommended approval for continuation funding.

MOTION to approve continuation funding for the grant *Children's Specialized Hospital Pediatric Primary Care ASD Medical Home* (CAUT15APL020) for year two continuation funding was approved with all in favor.

Grant # CAUT15APL025

Dr. Eggerding called for a motion to approve the grant *Autism Care Coordination Program* for year two continuation funding.

MOTION by Ms. Goldfarb to approve the grant *Autism Care Coordination Program* for year two continuation funding was seconded by Dr. Friedman.

Dr. Zanna noted the grantee has made significant progress in addressing the deliverables since the third quarter with the hiring of the project manager working with the Principal Investigator and her team. Their deliverables are presented in great detail with illustrations and narratives. It is clear they understand the requirements of the grant. The challenge during the first two quarters of the grant was in understanding the relationship between the deliverables with the project specific objectives and how to best integrate the two. Much can be learned from the outcomes of this grant about the challenges and possible solutions to establishing medical homes in pediatric primary care practices. Dr. Zanna recommended approval for continuation funding.

MOTION to approve continuation funding for the grant *Autism Care Coordination Program* (CAUT15APL025) for year two continuation funding was approved with all in favor.

Grant # CAUT15APL027

Dr. Eggerding called for a motion to approve the grant *Enhancement of Service and Technology Coordination to Establish a Medical Home for Autism at the Institute for Child Development (ICD), Hackensack University Medical Center (HackensackUMC)* for year two continuation funding.

MOTION by Ms. Goldfarb to approve the grant *Enhancement of Service and Technology Coordination to Establish a Medical Home for Autism at the Institute for Child Development (ICD), Hackensack University Medical Center (HackensackUMC)* for year two continuation funding was seconded by Mr. Macchiaverna.

Dr. Zanna noted the grantee's greatest challenge has been in filling positions resulting in the delay in implementing all proposed activities to meet the deliverables. It is anticipated they will make significant progress with the deliverables now that a program coordinator has been hired. The Principal Investigator has been active in implementation of the program specific objectives including meeting with five pediatric practices, setting up a dedicated phone line for the medical home, giving presentations and developing plans to establish an advisory committee with parent members. In addition, the grantee's Family Resource Specialist (FRS) from SPAN has spoken to more than 80 families providing information, support and assistance in obtaining services.

MOTION to approve continuation funding for the grant *Enhancement of Service and Technology Coordination to Establish a Medical Home for Autism at the Institute for Child Development (ICD), Hackensack University Medical Center (HackensackUMC)* (CAUT15APL027) for year two continuation funding was approved with seven in favor and one recusal.

V. NJ ACE Coordinating Center Update – Gerard Costa, Ph.D.

Dr. Costa presented a summary of the Coordinating Center's activities and services. He noted with the 6 new FY'16 clinical research grants recently approved by Council, the Coordinating Center staff will oversee a total of 28 grants, including 10 FY'15 grants, 6 FY'14 grants, 5 FY'13 grants and 1 FY'12 grant. Of the 28 grants, 3 are scheduled to close over the summer and 3 have been granted no cost extensions. Two grants have recently closed. Dr. Costa described progress in planning for the 2017 Summit and stated the application for approval of the Summit will be submitted to the Council's staff in June.

VI. Acting Executive Director Report- Martin T.Zanna, MD, MPH

This is the fourth meeting since Council has expanded its membership and Dr. Zanna is grateful the Council, under Dr. Eggerding's direction, is functioning so well due to the commitment and dedication of its membership. He then thanked Dr. Costa for his report.

Ethics Requirements

Dr. Zanna thanked those members who completed the on-line ethics training and sent their certifications along with the acknowledgement of receipt of the State Anti-Discrimination Policy to Linda. He commented it is a requirement to keep the documents on file verifying members are in good standing as Special State Officers. Members who have not completed the requirement are requested to do so within the next week.

SFY'17 RFA

The SFY'17 RFA is being finalized with an anticipated release date of mid-July, providing the SAGE application for the new initiative (basic research) is completed by then. We are also seeking clarification from the DOH regarding institutions outside of NJ applying for the RFA.

2015 Annual Report

Although the 2015 Annual Report is posted on Council's webpage we are exploring options for distributing to a wider audience either electronically or hard copies. If you have any suggestions, please let us know.

Note: Several members commented on the need to find ways to highlight the work of the Council, especially raising awareness among families. In general, families are not aware of what the Council does.

VII. Report of Revenues and Expenditures

The report was included in members' Council packets, for information.

VIII. Public Comments

No public comments.

IX. Adjournment

Dr. Eggerding asked for a motion to adjourn.

MOTION to adjourn by Ms. Goldfarb and seconded by Dr. Friedman was approved with all in favor.

The meeting was adjourned at 8:45 PM.